

## **New Directions for Missourians with Developmental Disabilities**

### **Executive Summary**

- ❑ There are 27,882 individuals with developmental disabilities served by the Department of Mental Health/Division of Mental Retardation and Developmental Disabilities (DMRDD) in Missouri. Of these, 15,017 receive only case management services, 11,490 receive services from community service providers, and 1,208 reside in state operated habilitation centers.
- ❑ A developmental disability is differentiated from other disabilities or mental illness because it is (a) manifested before the age of 22, (b) likely to continue indefinitely, and (c) results in substantial functional limitations in life areas such as mobility, language, learning, self direction, and independent living. Mental Retardation, Cerebral Palsy, Autism, and Down Syndrome are all examples of developmental disabilities.
- ❑ The Department of Mental Health operates Regional Centers that provide case management for individuals with developmental disabilities. The Regional Centers operate out of eleven principal sites and supported by numerous satellite locations. They are the primary points of entry into the system, determine eligibility, assessment, quality assurance and authorize funding for services with private community providers.
- ❑ It is essential to develop cost effective supports and services to keep people safe from abuse and neglect, avoid costly out of home placement, help families provide for their children when possible and maximize the participation of local agencies to stretch state resources.
- ❑ The need for services for people with developmental disabilities is increasing in Missouri. In March of 2005, there were 476 individuals on the waiting list for residential services and 2,761 waiting for a variety of in-home or family supports. The need for more services, the growing number of people waiting for services, and limited financial resources, are reasons to reform the developmental disabilities service delivery system.
- ❑ New Directions for Missourians with Developmental Disabilities offers a redesign of the current state operated system. This plan will replace the Regional Centers and utilize private entities to keep people safe from abuse and neglect, increase local participation, lessen the government role, avoid duplication, assure quality and efficiency, and assure that people with developmental disabilities live and work in the community of their choice. It will also stimulate the local economy as new jobs are created by the private sector agencies.
- ❑ The Department of Mental Health will no longer oversee the operation of the Regional Centers, but will instead monitor the system for abuse and neglect, service quality, fiscal accountability, and resource development. They will also manage the wait list for people needing services.

## **New Direction for Missourians with Developmental Disabilities**

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**Proposal  
October 11, 2006**

*We believe that...*

...people with developmental disabilities should be accepted and valued for who they are. They have talents and can contribute to society.

...an individual's needs are best determined and served at the local level.

...people with developmental disabilities and their families should determine the types of services that are best for them.

...service providers should be held accountable for making an improvement in the lives of people with developmental disabilities.

...people with developmental disabilities should have an economic opportunity – to work, succeed, and contribute.

...people with developmental disabilities have the right to be safe -- live free of abuse, neglect and exploitation.

The current environment and changes in leadership within the Division of Mental Retardation and Developmental Disabilities (DMRDD) offer a unique opportunity to dramatically reform the Missouri system of supports and services for people with developmental disabilities. We believe the needs of people with developmental disabilities are best determined and met at the local level with input from individuals who need services, their families and service providers.

Missourians would benefit from a community-based system of privately contracted organizations that will determine and be held accountable for the most appropriate means to deliver a system of supports and services to people with developmental disabilities when services are needed. Policy for this system should be developed with the meaningful participation and input from people with developmental disabilities, family members, community service providers and other stakeholders. Consumer involvement will help assure that there are opportunities for real choices. They understand that inclusion in the community will result in acceptance by the community, thereby reducing the need for specialized, segregated services.

The DMRDD can effectively contract with private not-for-profit agencies to deliver case management services, determine eligibility, manage local wait lists and provide and/or contract for a system of programs and services in their local areas. A localized system encourages partnerships between consumers, families and other community resources, facilitates the delivery of individualized services that are most effective and least costly and provides accountability for the safety of people with developmental disabilities as well as the efficient use of government funds. Administrative Agents will provide and/or contract for services with other providers in their area.

## **I. Outcomes.**

1. Each Administrative Agent (AA) is responsible for the following outcomes and others the DMRDD deems necessary for the well being of the people with developmental disabilities in that area. Failure to produce the following may result in cancellation of the contract:

- a) Reduce the incidents of abuse, neglect and mistreatment of people with developmental disabilities;
- b) Maintain case manager caseloads of 30 individuals or less;
- c) Reduce the number of people on the wait list for services (including those waiting to leave a habilitation center) and increase the number of people served annually by agreed upon numbers;
- d) Services offered are in direct response to the input from people with developmental disabilities and their families;
- e) The AA and all affiliated providers adhere to rigorous standards, achieve and maintain national accreditation in developmental disabilities services;
- f) Reduce the turnover of direct staff employed by the AA and affiliated organizations; and
- g) Establish services that allow people living in a habilitation center the opportunity to move into the community.

## **II. Requirements of Administrative Agents.**

- 1. Not-for-profit organization or any entity organized under SB40.
- 2. Nationally accredited by CARF or The Council in disability services.
- 3. Principal has minimum of 10 years experience providing services to people with developmental disabilities.
- 4. Single not-for-profit organizations or networks may apply.
- 5. The administrative agent must establish a separate and distinct board of directors to govern the operations of the AA.

## **III. Responsibilities of the Administrative Agent.**

- 1. The AA is responsible for developing a plan that will address and meet the needs of persons with developmental disabilities who reside in their area. The plan will address how the AA will support choice and increase opportunities for inclusion on the community.
- 2. The AA plan will address the needs of individuals with special needs (behavioral/medical) and develop the capacity to support those needs in the community. The AA may determine that the special needs of an individual cannot be adequately supported with existing services in the community. In such a determination, the AA will make an appropriate referral to another community setting if possible or state-operated program depending on the level and severity of the individual's need. If a referral is made to a state-operated program, the AA must first demonstrate that all attempts to support the individual in the community of choice have been unsuccessful. The AA must continue efforts to develop community services to provide necessary supports for persons placed in state operated programs.

3. Each AA will act as the single point of application, eligibility determination and referral for persons desiring to receive either information about community services or services within the service area.
  - a) If the person moves from one area of the state to another and wants to continue receiving community services, the level of state and federal financial support utilized to provide services and supports for that person is transferred to the person's new location.

### **Case Management**

1. The AA will ensure that each individual who is eligible has a qualified case manager of their choosing.
  - a) Case management may be provided by an accredited AA or affiliated provider;
  - b) Case managers must be an employee of an AA or an affiliated provider that is accredited and approved to provide case management services;
  - c) Case managers will not provide any other direct service except case management;
  - d) Case managers cannot supervise or be supervised by anyone responsible for the provision of services;
  - e) The AA or affiliated provider may be the provider of case management services and other services to the same individual;
  - f) Case managers must meet standards set by the AA including education, experience and fulfillment of ongoing training and education requirements; and
  - g) Caseloads may not exceed 30 persons.
2. The case manager will impartially:
  - a) Inform a person of the types and availability of community services provided within the service area, deciding which community services the person may need and assist a person in accessing the community services of the person's choice.

### **Affiliated Providers**

1. New providers must meet all guidelines and procedures established by the DMRDD to provide services prior to affiliation with the AA.
2. Community providers must be accredited by CARF or The Council in order to affiliate with the AA. A new provider may affiliate with the AA under a provisional status and will be given a minimum of 12 months to obtain accreditation. The AA may extend the provisional status at its discretion.
3. The AA will contract with community providers to ensure that sufficient services are available in the area. Using affiliated providers, people with developmental disabilities will have a choice of providers, an array of supports and specialized services for those with complex behavioral or health needs. The continuum of services should reflect the preferences of the people with developmental disabilities and their families in the area. The AA will ensure that each community service provider entering into an affiliating agreement abides by the procedures established by the AA and the DMRDD. In meeting this requirement, the AA may refuse to enter into or continue an affiliation agreement with any community service provider under any of these circumstances:
  - a) If the provider and the AA cannot agree upon suitable reimbursement rates for services;

- b) If the provider has established a pattern of failing or refusing to abide by procedures established by the AA, or failing to comply with its affiliation agreement with the AA; and/or
- c) If the AA demonstrates to the satisfaction of the DMRDD that being required to enter into the affiliating agreement would seriously jeopardize the AA's ability to fulfill its responsibilities.

### **Reporting Responsibilities of AA**

1. Collect and report to the DMRDD, all information requested including the following:
  - a) The plans of care detailing home and community-based services to be provided to persons served by that program;
  - b) Independent financial audits obtained by the AA, as well as any management letters generated as a result of the audits;
  - c) Any other information or records the AA has that the DMRDD needs in order to monitor how services are provided in the AA's service area;
  - d) Reports of all meetings of the Council of Community Membership and any recommendations made by the Council; and
  - e) Quarterly reports on the mandated outcomes for the people with developmental disabilities served by the AA including incidences of abuse and neglect.

### **Contracting**

1. Any AA failing to maintain compliance with the provisions of the contract include progress made towards measurable outcomes for the area may be subject to one or more of the following actions:
  - a) The requirements of a corrective action plan, approved by the DMRDD, with specific corrective or improvement activities identified and implemented, measurable outcomes and implementation timelines;
  - b) The requirement of a peer review process, with specific review and improvement activities identified and implemented, measurable outcomes and implementation timelines;
  - c) Suspension of part or all of the payments provided for in the contract until the violation is corrected; and/or
  - d) Cancellation of the contract.

## **IV. Quality**

1. The AA and affiliated providers will design annual quality enhancement plans and submit the plans and a record of progress to the AA and the DMRDD. The plans will include:
  - a) Training programs for direct staff and supervisors designed to lessen the likelihood of accidents and injury including medication errors and abuse;
  - b) Processes and documentation to frequently monitor community living homes to ensure the well being of the people served;
  - c) Documented surveys of satisfaction from people served and their families and actions taken in response to those surveys; and
  - d) Copies of a "Whistle Blower" policy and documentation of the distribution to direct staff.

2. The AA and affiliated providers will be immune from civil liability for any response to a request for information about the performance of any direct staff or their supervisor to provide care and support to people with developmental disabilities from a perspective employer.
3. The AA shall create an objective rating system for all affiliated providers to help consumers, families, guardians, case managers and other persons who may provide supports to persons with developmental disabilities assess the quality of a provider. This scoring system shall award points to an organization based on certain criteria, including the status and years of accreditation, certification programs for direct support staff, number of years in business, substantiated abuse and neglect investigations, turnover ratio of direct support staff and other meaningful criteria.

### **Safety**

1. The AA will ensure that each person and his or her family receiving services from the AA or an affiliated provider will receive training to recognize and report abuse/neglect. An abuse/neglect “tool kit” will be provided for all persons served including information about acceptable/unacceptable interactions, the rights of the person served and how to access assistance in an emergency.
2. The AA will ensure that the Person Centered Plan for each person addresses safety/crisis planning should they be subject to or witness abuse/neglect.
3. When an allegation of abuse or neglect has been substantiated against an individual they will be listed as ineligible for employment working with people with developmental disabilities by the DMRDD even if they appeal the findings. If they appeal and the substantiated finding is reversed then they will be eligible for employment working with people with developmental disabilities.
4. Legislation is needed to amend current child abuse protection laws to include mandatory reporting of abuse and neglect of any vulnerable adult.
5. DMRDD will create a toll-free hotline for the reporting of abuse and neglect of persons with disabilities by anyone at anytime.
6. The AA will assure that consumers, parents, guardians, family members and other individuals involved in the support of persons with disabilities have a non-biased and fair resource to help resolve conflicts, complaints and concerns by establishing an ombudsman office. Each local ombudsman shall report to a statewide ombudsman who shall monitor and report unresolved conflicts of interest to DMRDD who is responsible for quality of the system.
7. The AA will develop and support mandatory training criteria for any entity or their employees receiving state funds to support or serve a person with a developmental disability. Additional training programs shall be developed and supported either directly or by sub-contract to enhance the skills of employees who provide direct services. These programs should have minimum requirements for continuing education in order to be certified and approved to work with adults with disabilities.

## **V. Requests for Proposals.**

1. A Request for Proposals (RFP) will be issued when the DMRDD establishes a new AA. Every five (5) years thereafter a RFP will be reissued to solicit proposals for the AA. The existing AA and any other interested parties meeting the requirements may apply. If the AA contract is awarded to a different organization, the current AA, if a service provider, may become an affiliated organization.
2. The RFP will include requests for the following:

- a) A statement of the problems thought to exist with the current structure of community services for persons with developmental disabilities within that service area or areas and how the new or realigned AA will address those problems;
- b) A description of what specific services the AA will provide and a plan for how other service needs of the proposed service area will be met;
- c) A description of the planned structure of governance, organization, staffing and fiscal management procedures that will be used by the new or realigned AA;
- d) A long-range financial plan detailing how the new or realigned AA proposes to finance itself during the initial five-year period;
- e) A statement of the anticipated fiscal and service impacts that this new or realigned AA will have on all other affected service areas of the state;
- f) An endorsement of the proposal by the governing board or boards and chief executive officer or officers of any affected existing AA or an explanation of why an endorsement has not or cannot be obtained;
- g) Documentation of the experience and expertise of the applicant including years of experience serving people with developmental disabilities;
- h) Verification from national accreditation agency that the organization(s) have full accreditation, the numbers of years and service areas of accreditation and a copy of the previous two survey reports;
- i) Verification of not-for-profit status;
- j) A plan to meet the required outcomes; and
- k) A plan to give people living in habilitation centers access to services in the community.

### **Approval of Administrative Agents**

1. Before the approval or disapproval of a proposal to establish a new AA, or to realign the service area of one or more existing AA, comments from the following will be sought out by the DMRDD:
  - a) Consumer and advocacy organizations or representatives;
  - b) Other interested individuals and agencies; and
  - c) Providers in and near the proposed new or realigned service area or areas.
2. The DMRDD will be responsible for awarding AA contracts.

## **VI. Wait list.**

1. The DMRDD will maintain a statewide wait list and allocate “caseload growth” funding to each AA according to the need in that area. When funds become available through attrition or a reduction in services those funds will be redirected by the AA to meet the needs of persons within that area.

## **VII. Medicaid Waiver.**

1. The DMRDD has total responsibility for writing and amending all Medicaid waivers in accordance with the needs of people with developmental disabilities.

- a. The DMRDD will assure that sufficient Medicaid Waiver funds are made available to the AA according to their contract with the AA.

## **VIII. Habilitation Centers.**

1. The DMRDD will be responsible for the operation of the habilitation centers.
2. Each request for admission to a habilitation center will be submitted to the AA responsible for the county in which the person is currently residing.
3. When reviewing each request for admission to a habilitation center the AA will:
  - a) Determine whether or not the person is eligible for habilitation center services using state-established guidelines;
  - b) Inform the person, the person's family and the person's guardian if one has been appointed, of all services and supports that are available in or near the person's home county;
  - c) Offer to provide or arrange to provide these services and supports; and
  - d) Send a report to the director of DMRDD to justify each admission.
4. The AA will work with the DMRDD to annually review each person living in a habilitation center to determine if the habilitation center is meeting the needs as addressed in the person's support plan. The AA will ensure the persons support plans address issues preventing them from living in a less restrictive environment.
5. Assure that the person receiving services is informed about supports and services that are provided in the person's home county and that the person has been given the opportunity to choose to receive these services in his or her home county.

## **IX. Council of Community Members.**

1. Council of Community Members will be formed by each AA and approved by the DMRDD to help assure that needs are being met according to the plan developed by the AA.
2. Council membership will be made up of representatives from each of the following areas:
  - a) Person with a developmental disability;
  - b) Family member or guardian of a person with a developmental disability;
  - c) Representative from the AA;
  - d) Affiliates of the AA;
  - e) Representative from the habilitation center; and
  - f) Community members with related interests
3. AA will be responsible for reporting to the Council information about:
  - a) Abuse and neglect investigations and results;
  - b) Equitable access to services;
  - c) Case management services;



- d) Quality enhancement activities;
- e) Quality assurance results; and
- f) Conflicts of Interest and Dispute Resolution.

## **X. The Missouri Planning Council.**

1. DMRDD will solicit written input from the Missouri Planning Council regarding:
  - a) Geographic boundaries for each AA, based on population, diversity, transportation within the area and wait list;
  - b) Evaluation of the responses to the request for proposal;
  - c) Ongoing reviews of the quality of services within each AA region; and
  - d) Annual recommendations to address the statewide wait list for service.
2. The Missouri Planning Council will coordinate an ongoing peer review process that facilitates continual improvements in the quality of services of the AA and affiliated providers. The results of the peer reviews will be submitted to the DMRDD and the Council of Community Members.

## **XI. Dispute Resolution**

1. Each AA, in conjunction with the Council of Community Members, will develop and implement a dispute resolution procedure that will provide persons being served by the AA, or by any affiliated provider, with a means for resolving disputes that may arise. Grievances by a parent or individual should first be addressed to the provider, and if unresolved, then filed with the AA. Grievances by providers should first be addressed to the AA.
2. Each AA is responsible for forming a local “Commission” for the purpose of resolving disputes that cannot be resolved directly with the AA. The Commission is comprised of three (3) designated members from each of three groups: Board of Directors for the Administrative Agent, the Division of MRDD and the Council of Community Members.
3. If any grievance is not satisfactorily resolved at the level of AA the final recourse would be to file a grievance with the local “Commission.” The decision of the Commission is final.